THE MYOSITIS ASSOCIATION®

MYONews

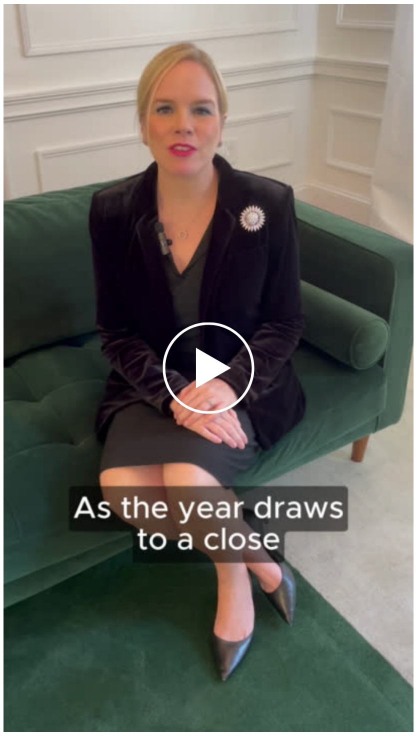
January 2024 | Issue One

It's not too late to make a difference!

We are so very grateful to those who contributed to TMA during our year-end fundraising campaign. As a nonprofit organization supporting the myositis community, TMA depends on financial gifts from individuals like you to fulfill its mission of improving the lives of those who live with these rare, debilitating diseases.

But it's not too late to make a difference! If you haven't already, please consider making a gift to TMA today. We are deeply grateful for your generosity!

DONATE NOW



THE OUTLOOK

The Myositis Association®

WINTER 2023
Quarterly Newsletter

News | **Page 4** | *Meet TMA's new executive director*
Myositis Awareness | **Page 8** | *Health equity for all*
Member Stories | **Page 10** | *Partners in the fight*

The Winter 2023 issue of The Outlook magazine is now available online. Meet TMA's new executive director, see highlights of TMA's Annual Patient Conference, read the latest news and member stories, and more.

READ NOW

Farewell and thank you, Rhonda!

We all knew Rhonda Buckley-Bishop would not be with us long. She was hired in January 2023 to serve as interim executive director to lead TMA until a permanent ED could be recruited.

But Rhonda was not just a placeholder. She efficiently and effectively led TMA through this challenging time of transition, working hard to set us up for success moving forward. When our new Executive Director, Paula Eichenbrenner, joined us in November, TMA was in a much stronger place as an organization, one that powerfully works to improve the lives of those who live with myositis.

We all knew it was coming. Still, it was a sad day when, on December 29, Rhonda cleared out her desk and walked out of the office for the last time. With the help of her company, Illumine Interim Executives LLC, she expects to join another nonprofit that needs her interim organizational help.

We are more than grateful for all of Rhonda's hard work and dedication to TMA's mission and her commitment to the myositis community. And we are happy to know that she will stay in touch and continue to support TMA from afar.

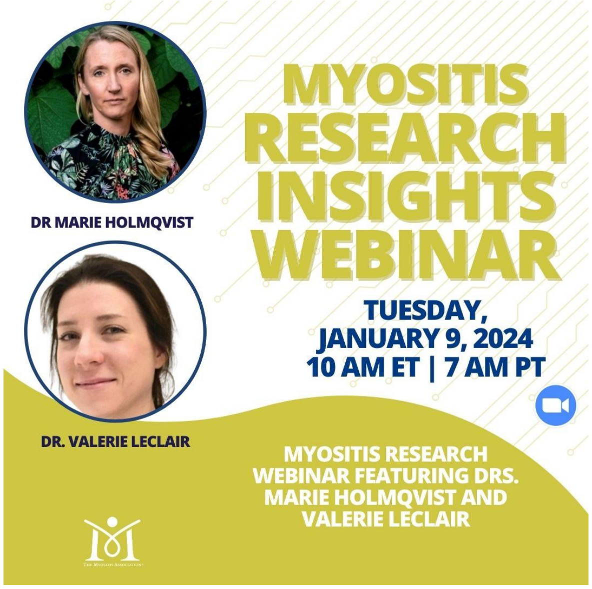
“We can't thank Rhonda enough for her incredible work this year at TMA,” says Dr. David Mochel, Chair of TMA's Board of Directors. “She poured her whole heart and soul into her work, and we are a much better organization now because of her and her incredible effort.”

We will miss Rhonda, and we wish her all the very best as she moves on to new adventures.

WATCH NOW

This year's Annual Patient Conference brought together the myositis community for an amazing experience of learning and sharing! If you missed this year's conference or you just can't wait to do it again, here's the scoop you've been waiting for:

TMA's 2024 Annual Patient Conference will take place on September 6-8, 2024 at the Hilton Baltimore Inner Harbor!



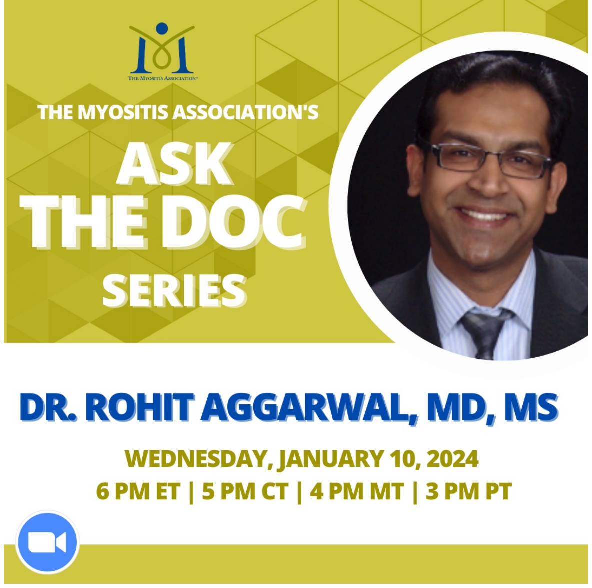
Myositis Research Insights Webinar featuring Dr. Marie Holmqvist and Dr. Valerie LeClair

Tuesday, January 9, 2024, 10 AM ET | 7 AM PT

Curious how an epidemiologist in Sweden would join forces with a rheumatologist in Canada to work on a PhD related to myositis? Dr. Marie Holmqvist of Karolinska Institute and Dr. Valerie LeClair of McGill University Medical Center's Jewish General Hospital will share how they came together to advance myositis research.

REGISTER TODAY

SUBMIT A QUESTION



Ask The Doc with Dr. Rohit Aggarwal

Wednesday, January 10, 2024, 6 PM ET | 3 PM PT

Have a burning question about myositis that just can’t wait for your next appointment? Global myositis expert Dr. Rohit Aggarwal has answers for you. Join this webinar to learn about aspects of this condition.

REGISTER TODAY

SUBMIT A QUESTION

Empowerment Clinic: How to Advocate for Myosits

Getting involved in legislative advocacy can be a rewarding and impactful way to contribute to the democratic process. While it may seem intimidating at first, there are steps you can take to make the process more manageable and approachable. In January, TMA will host a webinar featuring Rare Disease Legislative Advocates explaining how you can personally make a difference in the myositis community.

This webinar is in partnership with EveryLife Foundation

Webinar details coming soon! In the meantime, you can register to participate in Rare

Disease Week - registration opens January 3!

REGISTER HERE | SUBMIT A QUESTION

Meet and Greet with new TMA Leadership

February 1, 2024 at 4 PM ET | 1 PM PT

Bring your questions to this live, virtual meet and greet with the new TMA leadership. Get to know more about our new board chair and executive director while they also discuss the vision for the future. This webinar will be recorded and published on our website and YouTube channel.

REGISTER TODAY | SUBMIT A QUESTION

Have you considered becoming a support group leader for TMA?

Training is provided and you are supported every step of the way! You can be part of a group in your area and/or join the TMA Nationwide team where you co-lead with several experienced TMA group leaders who can provide additional guidance. And you don't have to be a myositis expert to serve in this role!

"As a support group leader, it is a unique privilege to help engage, educate, equip, and encourage those who are battling myositis. Meeting regularly to share 'who we are, where we are, and how we are' seems in the end to be more of a celebration gathering as we realize we are not alone. We are together, and we can live the best life possible under the circumstances. We are a band of warriors fighting the same battles, who together understand and empathize. We have become friends. More so, we have become family in a wonderfully unique way. " – Kent Yunker, Co-Leader, TMA Wisconsin

The next training session takes place virtually on March 29-30.

If interested, please schedule a 30 minute zoom meeting with Rachel Bromley, TMA Senior Manager of Patient Education, Support and Advocacy.

SCHEDULE NOW

Global Conference on Myositis 2024

The 5th biannual GCOM will take place in Pittsburgh on March 13-16. This international scientific meeting brings together the world's leading researchers and clinicians from all the different myositis specialties to share their unique perspectives on the science of myositis diseases.

Representatives from patient support organizations from around the world—including TMA—will also be there to network and collaborate and to emphasize the role and importance of patients in the work of the scientific community.

While this is not a patient conference and there will be no educational sessions for patients, the meeting will be held as a hybrid, and there is a reduced registration rate (€65 = ~$70) for patients who want to sit in on the scientific sessions and participate in the patient advocacy program.

If you'd like to attend, either in person or online, be aware that **early registration ends January 15, 2024.**

REGISTER TODAY

Tap into the power of peer support!

1:00-2:30 PM ET | 10:00-11:30 AM PT
FIRST SATURDAY OF EVERY MONTH

TMA NATIONWIDE
Myositis Support Group

Find encouragement and motivation to persevere through tough times. Connect and learn. Breakout rooms grouped by diagnosis and led by trained, certified peer leaders from across the nation!

Register Now!

2024 UPCOMING EVENTS

Tap into the power of peer support!

Did you know that if you are a person with myositis or caring for someone with myositis and feel you need support as soon as possible, you are welcome to attend any scheduled myositis meeting, even if not in your geographical area? Just check our events calendar and register for what interests you. TMA is an inclusive community and invites you to reach out as you need.

We would especially love to see you at TMA's Nationwide Myositis Support Group Meeting on Saturday, January 6, 2024 | 1:00 pm – 2:30 pm ET.

Visit the TMA Events Calendar to see and register for upcoming support and affinity group meetings, webinars, and more.

TMA Pod Naming Contest!

TMA plans to rebrand its popular myositis podcast in 2024! Our inspirational podcast programming aims to share strong stories that reassure our community there is life after diagnosis and fortifies them with hope and joy for their continued journey. This podcast is for everyone, whether you or your loved one were diagnosed recently, decades ago, or any time in between.

This contest closes on January 24, 2024. The winner will be announced in the February newsletter. The winner receives a $100 Amazon gift card!

What should we name it? Please submit your podcast title suggestion(s).

SHARE YOUR SUGGESTIONS

Johns Hopkins Myositis Center invites individuals diagnosed with MDA-5 dermatomyositis to take part in our study examining the microbiome.

If you were diagnosed within the past 3 years, you could be eligible!

Your involvement will deepen our understanding of dermatomyositis and potentially shape future treatments.

To see if you meet the criteria, please contact study coordinator, Zoë Hornberger, at Johns Hopkins University.

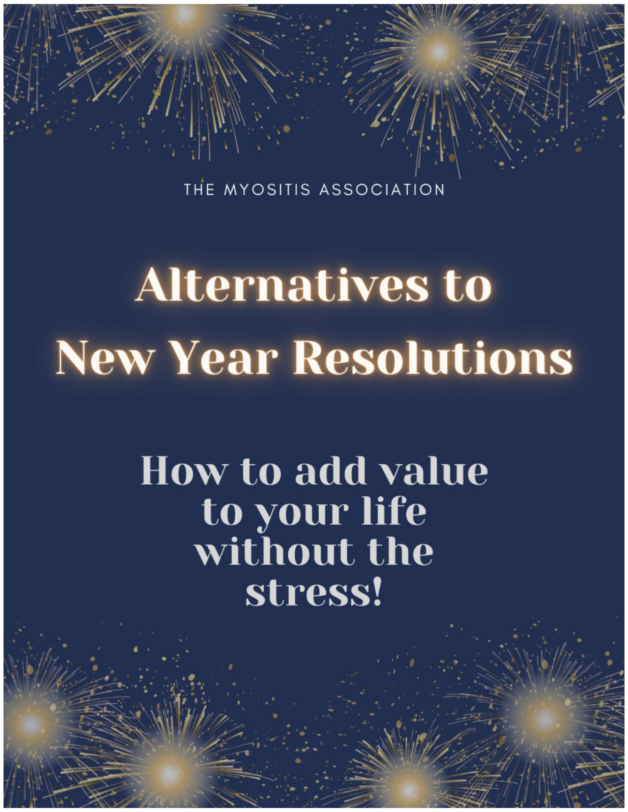
Email: **zhornbe1@jh.edu**
Phone:**(410) 550-9005**

Minding Your Mental Health

What we eat matters not just for our physical health but also for our emotional well-being. The Harvard Health blog reports on a set of studies that showed an association between a lower risk of depression and eating a diet high in fresh fruits and vegetables, whole grains, fish, and olive oil and low in saturated fat and animal products.

Another study reported in the journal PLOS ONE found that symptoms of depression were reduced in a group of young adults who cut down on processed foods, sugar, and carbs, and opted for a produce-heavy Mediterranean diet instead.

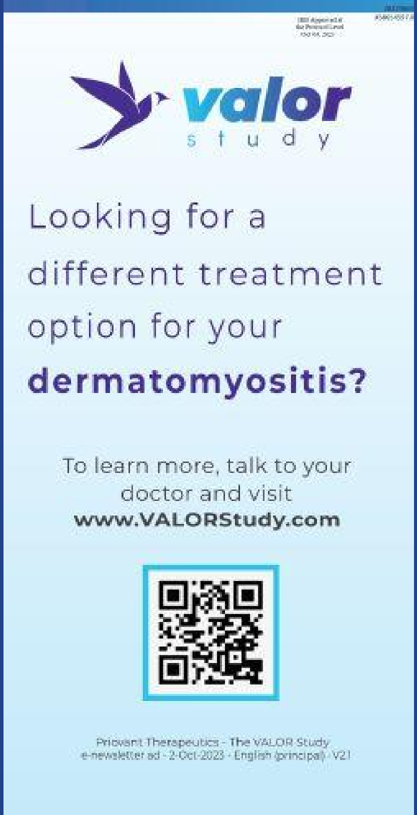
So eating a healthy diet can go a long way toward feeling better both physically and mentally!



New Year’s Non-Resolutions

Does the idea of setting New Year’s Resolutions stress you out? Here are some alternatives to this tradition that can help shape your year ahead without adding extra pressure. Choose your favorite one!

READ MORE



TMA's YouTube channel has been updated with links to all the most recent myositis webinars. Check out one of our playlists to learn more about myositis and available resources.

Recordings of TMA's 2023 Annual Patient Conference are now available!

The complete set of recordings will be delivered to you through a link where you can view them at your leisure. Those who attended the conference can order the recordings at a reduced price!

2023 Conference Recordings Pricing
Regular purchase price: $197
2023 Annual Conference attendees: $99

ORDER NOW

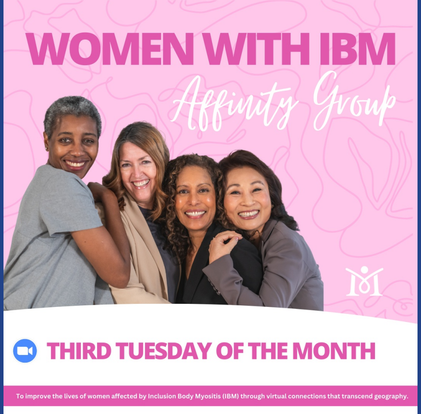
AFFINITY GROUP MEETINGS

TMA encourages members to attend as many meetings as fit your support needs. In addition to our geographically based support groups, TMA offers eight different affinity groups with members from all across the nation (and sometimes the world!).

TMA's affinity groups bring together members who share a commonality in addition to a connection to myositis. These groups provide a safe space that allows people to feel supported and respected. This is especially important for people of color, members of the LGBTQIA+ community, and other marginalized groups.

We invite you to learn more about TMA's affinity groups and how they are successful in engaging our community of patients, care partners, family, friends, healthcare providers, and industry partners!

LEARN MORE



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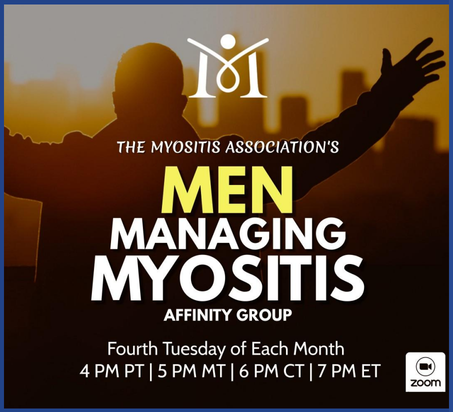

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Connect with us!